

# **Celebrating Milestones on the Road to Equality**

Ten years later, I see the Americans with Disabilities Act as a significant milestone, a tool, but hardly a journey's end. Not only are we still fighting for equality, but we also find ourselves fighting to keep the ADA!

Have there been changes? Yes.  
Has it leveled the playing field? Not entirely.  
Maybe lessened some bumps."

Phyllis Zlotnick  
P&A Advocacy Board Member

## **Annual Report 2000**



State of Connecticut  
Office of Protection & Advocacy  
for Persons with Disabilities

# P&A Vision Statement

The State of Connecticut will have a **legally based** protection and advocacy system that is deeply rooted in the **experience of people with disabilities** and **widely recognized, well respected and supported** for its **leadership, its commitment to community partnerships, equality and justice, empowering approaches;** and its ability to effectively **defend and advance the civil rights** of people with disabilities.

**Citizenship - Justice - Belonging**

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# A Message

from Executive Director, James D. McGaughey  
and P&A Board Chairperson, Darlene W. Foster

For the disability rights movement, the past year has been marked by a mix of celebration and anxiety.

We celebrated the tenth anniversary of the passage of the Americans with Disabilities Act (ADA) and twenty-fifty anniversary of the Individuals with Disabilities Education Act (IDEA). Each of these federal laws represents an important milestone on the road to equality and justice. Under the provisions of IDEA, an entire generation of children with disabilities has been able to grow up learning and living within their families and communities. Building on experience gained from earlier, more limited legislation, the ADA speaks loudly and clearly for the proposition that we all belong in American, and that, as a nation, we must be about the business of ensuring equal opportunity and access.



The year 2000 has witnessed enactment of a Work Incentives Act (Public Act 00-213) by the Connecticut General Assembly – legislation that allows people with disabilities who enter or return to the workforce to buy into continued Medicaid insurance coverage, thereby eliminating a major disincentive to seeking employment.

Indeed, considering the promise of this new legislation, and the tremendous demographic shifts, access improvements and collective consciousness raising that has accompanied IDEA and ADA, there is much to celebrate.

But there is also cause for anxiety. The ADA is being challenged in the courts and attacks on IDEA are being pursued with increasing vehemence and guile in Congress. Perhaps the most disturbing aspects of these challenges is the way they portray questions of fundamental civil rights as mere matters of federally imposed special programs or privileges – programs and privileges that somehow require state and local governments, and, by implication, non-disabled people, to meet unreasonable burdens. These challenges represent the politics of divisiveness and blaming, and ignore the shameful history of ignorance, rejection and neglect that have traditionally characterized responses to people with disabilities.

To advocates who had through these matters were being put to rest when the ADA and IDEA were enacted, finding a continuing need to justify their fundamental civil rights is unnerving. But history teaches that the road to full citizenship and quality is long and hard. Advocates must be prepared to teach, persuade and lead, and understand that while we are embarked on a difficult journey, the goal of achieving a rightful place in the world is worth the struggle.

The members of the P&A Board and Agency staff are proud of the work we are doing to help people with disabilities and their families along this journey. We are encouraged by the milestones we have reached, and confident that the directions and priorities we are pursuing are leading in the right direction.

## **P&A Advocacy Board Members**

*Kathryn Coffin*

*Catherine Cook*

*Darlene Foster, Chairperson*

*Eileen Furey*

*Sujella Gomez*

*Carol Grabbe*

*Nora Ellen Groce*

*Fritzie Levine*

*Edward Mambruno*

*Heidi Mark*

*Walter Pelensky*

*Cynthia Stramandinoli*

*Peter Tyrell, Esq.*

*Robert Wood*

*Phyllis Zlotnick*

# Introduction

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The Office of Protection and Advocacy for Persons with Disabilities (*better known as “P&A”*) is an independent State agency created to safeguard and advance the civil and human rights of people with disabilities in Connecticut. Through its work, P&A hopes to leave people with disabilities and their families better informed, equipped, and supported to advocate for themselves and others. Part of a nationwide network of protection and advocacy systems, P&A's federal mandates require organizational independence from service providing agencies and confers authority to access records, conduct investigations, pursue legal remedies, and educate policy makers.

P&A operates under both State and federal legislative mandates to:

- ◆ provide information, referral, and advocacy services;
- ◆ pursue legal and administrative remedies on behalf of people with disabilities who experience disability-related discrimination;
- ◆ conduct investigations into complaints from people with disabilities, and into allegations of abuse and neglect with respect to adults who have mental retardation (ages 18-59), and people in psychiatric facilities; and
- ◆ provide public education and training on disability issues and to inform policy makers about issues affecting people with disabilities.

# **P&A**

## **Year 2000 Priorities**

P&A is required to consciously prioritize amongst the myriad competing needs and worthy endeavors it could possibly pursue. After reviewing a number of possible priority areas, P&A's Advisory Board recommended six projects for action during the year 2000. These were:

1. Decrease exposure of people with disabilities to abuse and neglect
2. Protect the rights of persons in institutions
3. Pursue equal educational opportunities for children with disabilities
4. Monitor implementation of Titles II and III of the Americans with Disabilities Act
5. Protect the rights of parents with disabilities
6. Focus attention on the needs of people with disabilities in the criminal justice system.

Work on these six priority projects, as well as our state and federal mandates, is reported herein.



## Federally Funded P&A Programs

In addition to its state funded advocacy services, P&A operates the following federally mandated advocacy programs for people with disabilities:

- **P&A for Persons with Developmental Disabilities (PADD)** - The Developmental Disabilities Act requires P&A systems to be independent of service systems; to have access to client records; to have the authority to conduct investigations and to pursue legal and administrative remedies on behalf of clients of the DD service system; to provide information and referral services; and to educate policymakers about issues of concern to persons with disabilities.
- **Client Assistance Program (CAP)** - CAP provides consultation and advocacy assistance to applicants and recipients of services provided under the federal Rehabilitation Act. CAP's primary focus is helping clients of the vocational rehabilitation service system, most notably the Bureau of Rehabilitation Services (BRS), and Board of Education and Services for the Blind (BESB).
- **P&A for Individuals with Mental Illness (PAIMI)** - PAIMI investigates allegations of abuse and neglect and other complaints raised by people with mental illness who reside in supervised facilities, and advocates for appropriate discharge plans, consumer choice, and respectful, relevant supports.
- **P&A for Assistive Technology (PAAT)** - provides consumer education and representation in an effort to expand the availability of assistive technology devices and services for people with disabilities.

# What We Do

Support Individuals  
and Families

Defend the Civil Rights  
of Vulnerable  
Populations

Support Community  
Advocacy  
and Coalition Building

Undertake  
Systems Change  
Initiatives

# Support to **Individuals & Families**

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The Office of Protection and Advocacy for Persons with Disabilities strives to provide high quality, current information about disability rights and resources. Individuals and families receive assistance with clarifying issues and advice about remedies and potential courses of action. P&A staff also provide short and long term advocacy intervention consistent with agency priorities.

During the past year, P&A staff and subcontractors provided information and referral services to 7229 individuals seeking assistance. P&A staff members responded to calls concerning special education, housing rights and choices, and employment related inquiries. Callers also had concerns about personal decision making issues such as conservatorship, advanced directives and patients' rights, the Americans with Disabilities Act, transportation, health care, abuse/neglect, and assistive technology.

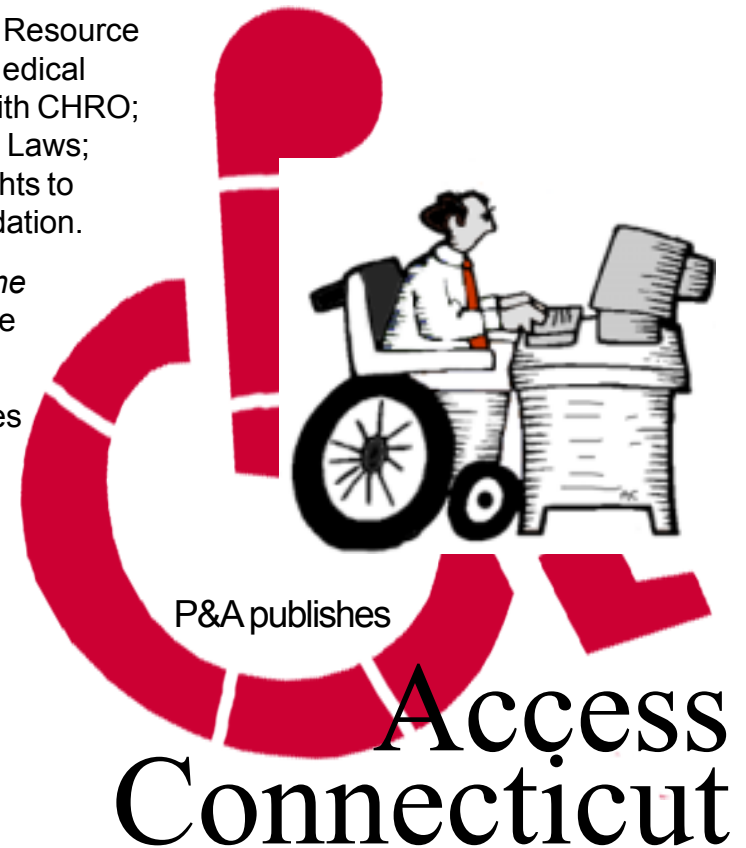
In addition, 930 individuals received advocacy representation from Protection and Advocacy advocates, attorneys and subcontractors. These individuals included 297 persons with mental retardation, 162 with psychiatric or emotional disabilities, 63 with learning disabilities, 48 with neurological impairments and 26 with hearing impairments. Sixty eight percent of the individuals were Caucasian, 11% Hispanic, 9% African American, 1% Asian and 11% other.

To further empower individuals and families:

- ♦ P&A maintained an internet site ([www.state.ct.us/opapd](http://www.state.ct.us/opapd)) which included current information targeted to individuals with disabilities and their families. Updated weekly, the site provided access to P&A self help literature, information about P&A programs and services, reports on current developments in the field of disability rights both on the state and federal levels, related sites of interest, and a summary of disability laws. During the Connecticut Legislative session, updates and alerts were posted with links to relevant bills and public acts.



- ◆ P&A's newsletter, "Disability Buzz", was published three times and distributed to over 1500 consumers, policy makers and disability organizations throughout Connecticut. The Buzz featured disability issues, legislation, upcoming events, Q&A on a variety of topics, and highlights the work done by P&A staff.
- ◆ P&A staff participated in 87 training events including media events, fairs, presentations, and focus groups. Approximately 1,645 individuals benefited from these events. Over 7,500 P&A publications and 1,500 publications from other sources were distributed.
- ◆ On July 26, 2000, in celebration of the 10<sup>th</sup> anniversary of the Americans with Disabilities Act, P&A published an insert in The Hartford Courant. The insert, distributed to 220,000 readers, was designed as a resource guide, with key agency listings and phone numbers. Accessible Connecticut businesses, municipal facilities and employers were highlighted. Common construction errors and proper accessible features were identified.
- ◆ P&A self-help booklets were updated and reprinted, including a Disability Resource Directory. Booklet topics included Building Accessibility; Access to Your Medical Records; Accessible Modes of Transportation; How To File a Complaint with CHRO; Your Rights In a Psychiatric Hospital; About SSI; Connecticut Fair Housing Laws; Your Rights and Responsibilities in Making Medication Choices; Your Rights to Vocational Rehabilitation; and Guardianship for People with Mental Retardation.
- ◆ A new booklet summarizing *Connecticut Public Act 99-210 Concerning the Physical Restraint of Persons with Disabilities*, was added to the available self help booklets. All booklets have been translated into Spanish.
- ◆ P&A's community development staff supported by case services advocates began work on a Family Resource Manual to be released in the spring of 2001.
- ◆ In the spring of 2000, P&A's Client Assistance Program initiated a series of consumer choice focus groups in collaboration with the Bureau of Rehabilitation Services (BRS), Board of Education and Services for the Blind (BESB), and Connecticut's five independent living centers. Individuals with disabilities participated in suggesting improvements to the vocational rehabilitation process. A report was written and distributed to forum attendees, advisory councils, and key vocational rehabilitation personnel.



## P&A Support in Action #1

### John Huminski – An ADA Milestone at the YMCA



**John Huminski**, a very athletic, 57 year-old man with cerebral palsy hopes to compete in the paralympics. After 25 years of membership, his local YMCA would not allow him to use the facility unless he brought someone to help him get in and out of the pool and assist him with showering and dressing. Initially, he complied with these conditions, but assistance from family members and others proved unreliable. Even John's Department of Social Services case worker tried to find funding to help pay for an assistant. He was being denied access to the YMCA and called P&A for help.

P&A's Americans with Disabilities Act (ADA) team members contacted the YMCA and spoke with the Director of Membership Services. She expressed concern for John's safety while using the pool, shower and dressing areas and was adamant that he could not use the facilities without personal assistance. The YMCA wanted to accommodate John and seemed open for suggestions.

A meeting was held with John, his brother, YMCA staff, P&A advocates, the DSS social worker, and an advocate from the local independent living center. The group toured the YMCA facilities including the pool and shower areas. A demonstration of the pool lift revealed that a faulty installation made it very difficult to use independently. In the locker area, an unsteady plastic chair had been provided for John to use as he transferred from his wheelchair to the shower. The showerhead was not at an accessible height and additional grab bars were needed.

The YMCA agreed to make changes to the lift and to make minor modifications to the shower facilities to create an accessible area for John. P&A volunteered to contact the pool lift manufacturer. The DSS Social Worker agreed to assess funding possibilities for an assistant for John under the Community Based Services Waiver, while the representative from the local independent living center offered to help locate personal care assistants in the area.

Another meeting was held after John reported that the YMCA had not made any improvements after several months. The Director of Membership Services also was not returning P&A telephone calls. P&A discovered that the Membership Director had been procrastinating because of her own paternalistic fears about John's disability and safety. The new Director of Program Development at the YMCA, however, considered John an asset. She agreed to make all the necessary changes and hoped that John would help the YMCA with disability membership.

The pool lift has been fixed. The YMCA has installed a hand held shower head; a shower wheelchair to provide stability when John uses the shower and pool deck; additional grab bars; and roll out, non-slip rubber mats in the shower and pool deck areas. John is back at the YMCA. He is not just a member but has now become a valued community resource as a mentor for other people with disabilities.

**"Not just a  
member  
but a  
valued  
resource."**

## **P&A Support in Action #2**

### **Charlie – An IDEA Milestone**

Joan, a single parent, called P&A about her son, Charlie, who was constantly getting into a lot of trouble in his classes. He had been suspended numerous times for violating school rules. He wasn't doing his work in class or at home and was failing all his subjects. Charlie had been placed in an alternative class setting for "problem students" and that wasn't working, either. He didn't want to be there — didn't like the "problem student" label and didn't want to be considered "different." Joan lost her job because of Charlie's constant suspensions and the school's repeated calls to come and get Charlie and bring him home.

Joan told her P&A advocate that she struggled to be heard and listened to at Planning and Placement Team (PPT) meetings. Nothing worked. She knew Charlie could succeed given the appropriate supports. P&A carefully reviewed Charlie's file and it became clear that Joan and her son would require a great deal of support. Joan was unable to clearly articulate the issues and Charlie refused to say a word.

The P&A special education advocate attended a PPT meeting with Joan to request that evaluations necessary to determine if Charlie had a learning disability. Despite initial resistance, the school district did agree to the evaluations and recommendations made by P&A. Once the evaluation was completed, PPT members reconvened to review the results and to develop an appropriate Individual Educational Plan (IEP) to meet Charlie's needs. A behavioral intervention plan was developed. Outside counseling was arranged and the school district retained an evaluator to consult with team members on a regular basis. The school agreed to discontinue suspensions and calls asking that Joan remove Charlie from school. An appropriate community-based transition plan was developed. The school made a commitment, Joan made a commitment, and, most important, Charlie made a commitment to stay in school.

Charlie successfully remains in school and benefits from his program. Joan recently contacted P&A to say that she is able to go to work with peace of mind and that Charlie will be graduating from high school this year. He works part-time at a lawn service company and his long-term goal is to own his own business someday.

**“Sometimes we moved two steps ahead and three steps back. But everyone became committed to keeping Charlie in his classes so he could make progress.”**

### **P&A Support in Action #3**

#### **Mary Muccio Returns to Work– A Rehabilitation Act Milestone**

Mary Muccio was out of work and struggling with a physical disability when she turned to the Bureau of Rehabilitation Services (BRS) to obtain the assistance she needed to return to work. Although determined eligible for BRS services, Mary became frustrated by the lack of contact with her BRS counselor. Eager to return to her job at the Department of Transportation, Mary purchased a manual wheelchair, paid for modifications to her vehicle, sold her home and moved to an accessible apartment. She was determined to get her life back on track no matter what it took.

Mary called P&A to register for an upcoming Consumer Choice focus group sponsored by P&A's Client Assistance Program (CAP). During the conversation, she expressed her frustration to CAP advocate Todd Higgins who learned that after Mary's initial fruitful meetings with her BRS counselor, she had been unable to reach him again.



CAP advocate, Todd Higgins, was surprised to learn that when Mary purchased the wheelchair and adaptive controls and moved from her home, she had no idea that these were areas where BRS could have assisted her. He explained to Mary that her counselor should have informed her that BRS can purchase equipment not covered by her medical insurance, her car could have been modified at the Bureau's expense and, most importantly, that she should have been informed that home

modifications could have been made with BRS financial support. Because Mary was not informed, she had spent over \$4,000 on equipment and sold her home.



Mary Muccio and P&A advocate Todd Higgins

Armed with this information and the new knowledge that her employment plan had not been developed in a timely manner, Mary called a meeting with her BRS counselor. Given the complexity of the situation, a P&A advocate attended with Mary. She requested reimbursement for the equipment but did not elect to pursue compensation for the loss of her home. The BRS counselor agreed that if he had written the employment plan in the fall of 1999, it would have included all of the items she purchased. Mary proceeded to request reimbursement from BRS for these expenses, but the agency replied that they would not reimburse her because she had not received prior written approval for the expenditures.

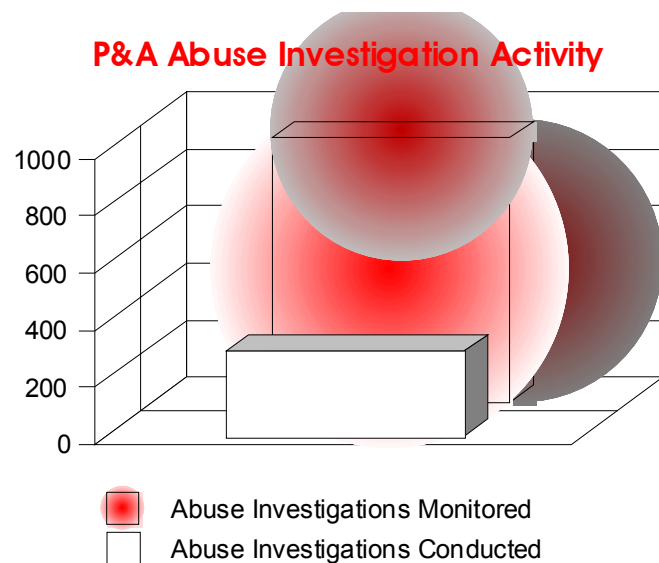
Unhappy with BRS's decision, a request was made and granted for an informal administrative review with the District Director of BRS. The request included a stipulation that the grievance not be heard by the same

District Director involved in making the decision to deny Mary's claim for reimbursement. The stipulation was granted and another Director was assigned.

The informal review took place and Mary prevailed. The District Director found that her BRS counselor had been negligent in explaining the nature and scope of services available to Mary and did not develop her employment plan in a timely manner. Mary was reimbursed for all the equipment that she had purchased in order to return to work. When asked if we could photograph her and tell her story for this Report, Mary replied, *"Anything for you - just name it!"*

# Defending the **Civil Rights** of Vulnerable Populations

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Federal and state mandates require P&A to defend the civil rights of vulnerable people. This includes investigating allegations of abuse and neglect, and intervening on behalf of people whose fundamental rights are in jeopardy.

- P&A's state mandated Abuse and Neglect Division received a total of 1373 reports of suspected abuse or neglect of persons with mental retardation during the 1999-2000 year. Of these, 265 investigations were conducted by P&A staff, and 929 were conducted by other agencies and monitored by P&A for completeness and accuracy. 179 reports did not fit statutory requirements.
- Eligible individuals received 442 units of information and referral services from the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program and 53 individuals were provided direct representation.
- P&A was instrumental in the establishment of a Peer Engagement Specialist Pilot program within the Department of Mental Health and Addiction Services. Peer engagement specialists are persons with psychiatric disabilities who will work with clients with psychiatric disabilities in a non-threatening, non-coercive way to help them get the community based mental health services best suited to them. P&A continues to be instrumental in the implementation of the program.



**P&A distributed  
educational posters  
to Connecticut  
treatment centers**



**about civil rights  
protections provided  
by Public Act 99-210.**

- ♦ The Abuse and Neglect priority team hosted an advanced training in program monitoring and conducting systemic investigations. The team also researched and compiled an investigation training manual.
- ♦ P&A staff participated in the planning and implementation of a statewide Shaken Baby Conference.
- ♦ P&A educated individuals, agencies and organizations about the Public Act 99-210, An Act Concerning the Physical Restraint of Persons with Disabilities. An educational poster has been distributed to all treatment facilities in Connecticut.
- ♦ The Institutions priority team conducted a comprehensive survey of Residential Care Homes with an emphasis on determining what life is like for the people with psychiatric disabilities who live there. A final report is ready for distribution.
- ♦ PAIMI staff collaborated with mental health consumers to complete Psychiatric Facilities Report Cards, focusing on patients' rights, at over 40 public and private psychiatric hospitals in Connecticut. Information on patient's rights was disseminated at each hospital during the report card evaluation. A report will be distributed to the evaluated facilities.
- ♦ P&A advocates and attorneys continued to represent individuals with brain injuries and the Brain Injury Association of Connecticut, Inc., in a class action lawsuit to provide a remedy for those persons with brain injuries currently housed inappropriately in state institutions.

## **Rights Protection in Action** - Abuse/Neglect Investigation Makes The Difference

*Due to client confidentiality, the name of the victim has been changed.*

In late 1999, a city police department received a phone call about a situation involving a mentally retarded adult living in “deplorable conditions.” The police confirmed that Fred did appear to be an adult with mental retardation and that he was living in a state of neglect. They contacted the Department of Mental Retardation (DMR) and reported that Fred was “covered in urine, feces and filth.” Later on the same day, the police returned to Fred’s residence with a DMR case manager. By then Fred had been given cleaner clothing, but the case manager noted that he looked severely underweight and could not or would not speak to anyone.

Fred was not previously known to DMR. He had been living for several years alone with his mother, who indicated that she was his caretaker. Both the police and the case manager attempted to speak with Fred’s mother about his obvious need for services, but she made it very clear that she did not want her adult son receiving any DMR support services.

Under P&A’s abuse investigation statute, withholding necessary services may constitute abuse or neglect. After the DMR case manager called P&A, and as required by statute, P&A investigators requested Immediate Protective Services from DMR to ensure Fred’s ongoing health and safety. Specifically, P&A requested that Fred immediately be seen and evaluated by a medical professional and that he be placed in a safe environment while an eligibility determination for DMR services was initiated on Fred’s behalf.

Fred was taken to the hospital for examination. The medical evaluation indicated that Fred was very underweight, but there was no apparent health issue which required medical treatment. DMR determined that rather than place Fred somewhere else, the agency would instead provide intensive in-home support services. The necessary paperwork to determine DMR eligibility was initiated and the family was provided with bed pads in order to assist in managing Fred’s incontinence.

P&A investigators went to the Fred’s residence a few days later and found him to be in substantially the same living conditions as had been earlier reported. Fred was lying in bed completely soaked with urine. The odor in the room was so strong that investigators found it difficult to remain inside. The room was infested with flies and it appeared that the carpet was thoroughly stained with urine and feces. The windows were sealed shut. Fred did not respond to any questions, instead pulling the wet covers almost completely over his head as if to hide.

The investigators went to DMR's regional office to relay what they just witnessed and resubmitted the Protective Service request that Fred be immediately provided with an alternative residential setting. However, rather than remove Fred, DMR initiated an appointment for Fred's mother to apply for Title XIX monies for home health care services, payments for the evaluations to determine his eligibility for DMR services, and disposable undergarments. Fred was eventually accepted as a DMR client and a DMR support worker was assigned to visit two or three times a week to monitor Fred's safety. When prearranged visits were scheduled, according to DMR, Fred appeared clean and had fresh bedding. Fred's mother, however, continued to refuse support

services and eventually began refusing DMR access into the apartment all together.

**“There was Fred,  
dressed very neatly  
in a dress shirt and  
pants, clean-shaven  
and smiling.”**

P&A investigators made an unannounced visit to see Fred. He was found cowering barefoot in the bathroom, looking even thinner than before and wearing sweatpants soaked with urine. Fred had open sores on his arms and a dirty scraggly beard. His bedroom was infested with roaches and rodent droppings and his bed mattress appeared to have dried blood stains on its surface. Fred remained silent and would not respond to anyone.

P&A again requested DMR to find an alternative residential placement and requested that his family have no unsupervised visits until further notice. This time he was removed from the home.

How is Fred doing now? The Court of Probate considered the issue of whether Fred should be placed outside of the home against his family's wishes. Fred's court-appointed attorney agreed with P&A and DMR that Fred should remain in his new residential setting, and the judge ruled in favor of Fred's placement. As one of the P&A investigators entered the elevator at the Probate Court building, he noticed three men entering behind

him - two of the men were talking and the third man was smiling. He looked again and barely recognized him. There was Fred, dressed very neatly in a dress shirt and pants, clean-shaven and smiling.

# Support for **Community Advocacy & Coalition Building**

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P&A provides assistance to community-based advocacy groups in many forms: consultation on organizational development or specific advocacy issues, co-sponsorship of training activities, staff support for local organizing activities, and coalition building. P&A also supports the development and expansion of a number of statewide and community-based advocacy organizations:

- ◆ The Connecticut Access Monitoring Project of the Americans with Disabilities Act Coalition of Connecticut (ADACC) to address the access mandates of the Americans with Disabilities Act and the State Building Code.
- ◆ AFCAMP, a parent advocacy group designed to organize African-American and Caribbean-American parents of children with disabilities in the City of Hartford. This year, the group conducted monthly trainings on a wide variety of special education and disability topics. The group has more than doubled over the past year to a membership of over 200 and is currently preparing to apply for non-profit status.
- ◆ Padres Abriendo Puertas, a grassroots, Latino parent organization that advocates for the elimination of educational, linguistic, political, cultural, and social barriers that result in educational segregation of children with disabilities.
- ◆ Citizen Advocacy Program of Eastern Connecticut (Colchester) seeks interested citizens who will become advocates for persons with disabilities. Citizens are matched with people who have disabilities according to the circumstances of each individual's situation.

## Advisory Councils, Boards, Task Forces and Committees

P&A staff also participate on a variety of advisory councils and task forces to improve services, expand resources, and protect individual rights:

Olmstead Coalition's Independent Living focus group  
Children's Behavioral Task Force  
Cultural Access Initiative  
Work Group on Prison Issues  
Bureau of Rehabilitation Services Advisory Council  
Board of Education and Services for the Blind Advisory Council  
State Building Codes Training Council  
State Independent Living Council  
State Department of Education Special Education Advisory Board  
State Department of Mental Retardation Investigations Division Advisory Board  
State Department of Administrative Services "Employability" Task Force  
State Interagency Council for Birth to Three  
Governor's Task Force for Justice for Abused Children  
State Department of Social Services Adult Protective Services Collaborative  
State Council on Developmental Disabilities  
State Department of Mental Retardation Mortality Quality Assessment Board  
Family Support Connecticut  
ConneCT Management Advisory Committee  
Permanent Commission on the Status of Women  
Capitol Area United Way Allocations Committee  
Connecticut State Employee Campaign for Charitable Giving  
Women's Health Agenda

- ◆ The Connecticut Women and Disabilities Network (CWDN) provides support and education to girls and women with disabilities and works to change societal attitudes and practices to enable women with disabilities to achieve equality.

In addition, P&A staff were engaged in the following community support activities:

- ◆ Offered 87 disability rights training sessions on IDEA, patient rights, state and federal fair housing laws, Sec. 504 of the Rehabilitation Act of 1973, and the ADA to 2,480 individuals.
- ◆ Collaborated with the ADA Coalition of Connecticut and other disability groups to host a celebration of the tenth anniversary of the ADA and twenty fifth anniversary of the Individuals with Disabilities Education Act. The rally, at the Legislative Office Building, included speakers, entertainment, voter registration, and inspiring stories.

- ◆ Participated in the implementation and planning of *Family Day*, a yearly, statewide event celebrating Connecticut's families.
- ◆ Spearheaded the formation of a collaboration between P&A and several non-profit organizations aimed at making mammography services accessible and available to women with disabilities.

Collaborators include the P&A-supported organizations Connecticut Women and Disability Network (CWDN) and the Americans with Disabilities Act Coalition of Connecticut (ADACC).

- ◆ Provided technical assistance including conducting grant searches, developing funding request proposals and reviewing grant applications for 60 organizations.
- ◆ Participated in planning and implementing a four-day Youth Leadership Forum held at the University of Connecticut. The Forum focused on educating and supporting high school students with disabilities, with an emphasis on each student developing a personal leadership plan. Twenty seven students from across the state participated.
- ◆ Sponsored training on the Connecticut Neighborhood Assistance Act Program for 20 community based disability organizations.
- ◆ Conducted fundraising, grant writing, and board development workshops for non-profit organizations and government agencies, including Department of Mental Retardation's Birth to Three System and the Central Connecticut Mental Health Board.
- ◆ Served on a committee to plan and execute a major conference focusing on people with hidden disabilities.



## Building Youth Leadership

## Community Advocacy in Action

### "The Maria Sanchez Project"



The Maria Sanchez Project, developed with the assistance of P&A special education and community advocates, provided small group training to parents of children with disabilities on how to effectively negotiate the PPT process. The training was conducted in small groups and one on one, and involved P&A attendance at some Planning and Placement Team (PPT) meetings to provide a model for parents to acquire advocacy skills and techniques. Parents learned how to help themselves with the goal of providing peer support to another parent at PPT meetings.

A training module was developed that included opportunities for role-playing and the taping of typical scenarios that may arise during meetings and negotiations. As the sessions progressed and the parents became more empowered and confident, certain parents emerged expressing the desire to become peer supporters. Lourdes and Ofelia (pictured at left) provided support to each other when navigating the special education maze on behalf of their children.



# Systems Change Initiatives

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Systems change activities include those strategies pursued by P&A staff that result in positive changes in government, human services, and other social systems that serve individuals with disabilities. P&A 's six priority teams accounted for much of the systems change activity over the last year.



P&A Staff Review Plans for the Amistad

- ◆ P&A played a major role in an initiative with the Department of Information Technology and the ConneCT Management Advisory Council's Subcommittee on Accessibility to ensure that all Connecticut's governmental web become universally accessible by January 2002. To celebrate the 10<sup>th</sup> anniversary of the ADA and to kick off the initiative, P&A brought in a speaker and pioneer of web site accessibility at a special meeting for state web developers.
- ◆ The Client Assistance Program (CAP) began its involvement with the eight regional work force boards currently overseeing the new one stop employment centers. CAP staff members met with all of the one stop centers, introduced the CAP program and distributed CAP literature. Future plans include site visits to the one stop centers and presentations to staff.



# Legislation 2000

P&A monitored, commented on, and educated policy makers on the following legislation which was enacted during the 2000 General Assembly session:

- ◆ A “work incentives” measure that will allow people with disabilities who enter the workforce to remain eligible for (or, depending on income, buy into) Title XIX (Medicaid) health insurance. This legislation was initially sponsored by a P&A-supported community group, the Connecticut Women and Disability Network.
  - ◆ Creation of a pilot “peer engagement specialist” program within the Department of Mental Health and Addiction Services to demonstrate the viability of non-coercive strategies to engage reluctant mental health consumers in recovery-oriented treatment. (While only funded at modest levels, adoption of this measure instead of a rival proposal that had called for court-ordered outpatient treatment furthers a balanced and fundamentally positive, respectful direction for the mental health service system.)
  - ◆ Clarifying and strengthening the identity of the Office of Protection and Advocacy as a source of safeguarding and advocacy representation by eliminating a conflicting role (paying for court-ordered evaluations in sterilization proceedings), and protecting the confidentiality of certain client information.
  - ◆ Allowing school systems to sell, loan or transfer adaptive equipment purchased for particular students to those students when they leave school without going through cumbersome “surplus” procedures.
- ◆ P&A staff, together with other disability rights advocates, worked to ensure that the reproduction of the Freedom Schooner Amistad was accessible to persons with physical disabilities. While the Amistad was under construction, P&A approached its Captain and financial sponsor with concerns about access to the deck. Disability rights groups, including P&A, pursued the access issue. A lift was designed and installed allowing all persons to experience the feeling of being on deck!
  - ◆ P&A continued its monitoring responsibilities pursuant to the consent decree developed during 1998 regarding deaf and hard of hearing individuals. The consent decree addressed the lack of effective communication available in the 32 acute care hospitals in the state. During this year, the U.S. Department of Justice gave P&A investigatory authority to conduct compliance visits at any Connecticut Hospital. P&A received approximately 6 complaints from consumers in the past year and are in discussions with the hospitals to correct and prevent future problems.

- ◆ The Americans with Disabilities Act team reviewed and compiled information received from a surveys to determine the level of municipal compliance with Title II of the Americans with Disabilities Act in Connecticut. The team provided technical support the Access Monitoring Project being implemented by the ADA Coalition of Connecticut. Contacts were made with members of the deaf community to assist the team with a better understanding of access to emergency services as they relate to persons who are deaf or hearing-impaired. The team developed and piloted a new case review system and assisted approximately 100 callers with ADA priority related issues.
- ◆ The Parents with Disabilities priority team held a conference, “Exploding the Myth”, in June that focused attention on the issues facing parents with disabilities. Conference attendees included parents with disabilities, advocates, experts and attorneys. The team also produced a resource listing to help parents with disabilities at risk of losing their parental rights.
- ◆ The Abuse and Neglect priority team researched and developed a resource guide on abuse/neglect prevention and awareness for persons with disabilities of all ages. The additional work of this team is highlighted in the “Defending the Civil Rights of Vulnerable Populations” section.
- ◆ The Institutions priority team conducted two rights-oriented presentations for parents with children who reside in residential facilities. A more detailed description of the work of this team is highlighted in the “Defending the Civil Rights of Vulnerable Populations” section.



## Parenting with disabilities **EXPLODING THE MYTH**

- ◆ The Criminal Justice priority team sponsored a three part Dialogue that addresses issues facing persons with disabilities in the criminal justice system. The Dialogue series brought together persons with disabilities and professionals such as public defenders, correction officers, sheriffs, mental health advocates, non-profit agencies, and court support services personnel. The participants had an opportunity to network, collaborate and gain a better understanding of the criminal justice system as a whole.

## Systems Change in Action #1

### **Citizenship – A Civil Rights Milestone**



Changes in the Immigration and Naturalization Act expanded citizenship rights for people with disabilities.

The Office of Protection and Advocacy represented several families whose adult children with mental retardation, autism and other cognitive disabilities were barred from becoming citizens because they could not understand the meaning of the oath. Earlier appeals to the Immigration and Naturalization Services were unsuccessful. P&A contacted the Office of Senator Christopher Dodd to investigate the possibility of changing the Immigration and Naturalization Act.

Connecticut Senator Christopher Dodd co-sponsored a Senate bill to change the law and P&A worked diligently to educate Connecticut's Congressional delegation and kept the families informed about the bill's progress.

At a press conference held at P&A, Senator Dodd announced a new law that removes the significant barrier that prevented people with disabilities from becoming naturalized U.S. citizens.

## P&A System Change in Action



# Every 1 Counts

**EVERY 1 COUNTS**, a major P&A voter accessibility initiative, was a collaboration with the Office of the Secretary of the State, and the University of Connecticut's A.J. Pappanikou Center for Disabilities Studies.

Project staff educated voters with disabilities about the importance of voting and their right to equal access at the polls. With the assistance of project trained volunteers, Connecticut polling places were surveyed for accessibility. The Office of Protection and Advocacy also provided technical assistance and training to Registrars of Voters to ensure that voters with physical and/or communication disabilities encounter a positive voting experience.

Approximately half of Connecticut's polling locations were surveyed and municipalities have removed barriers that prevent persons with disabilities from voting. The Project will continue during 2001.

# Fiscal Facts & Figures

In the fiscal year ending June 30, 2000, P&A had a total operating budget of \$3,469,082. Of this, \$2,515,543 or 72.5% was state funded and \$953,539 or 27.49% was federally funded. Personal services expenditures comprise 84% of P&A's General Fund Budget with an additional 9% expended on contracts and outside services. The remaining 7% was expended on necessary expense items including supplies, equipment, telephone, postage, and printing.

## **P&A federal expenditures for fiscal year 2000**



P&A's Business Office staff,  
Francis Dwyer and Kerry Kudelchuk

Client Assistance Program	\$120,188
Protection and Advocacy for Individuals with Mental Illness	\$286,894
Social Services Block Grant	\$198,878
Administration on Developmental Disabilities	\$261,858
Protection and Advocacy for Individual Rights	\$ 58,208

# Issues Affecting People with Disabilities

## as Reflected by Agency Priorities

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Section 46a-13 of the General Statutes requires that a portion of P&A's annual report concern the status of services for persons with disabilities. Because the agency's mission focuses on defending and advancing the civil and human rights of people with disabilities (as opposed to providing regulatory oversight or general quality assurance), this section of the report has historically looked at these issues from a disability rights perspective. In addition, because Congress recognized when it established federal requirements for protection and advocacy systems that the need for advocacy services would always outstrip available resources, it required P&A systems to develop an annual statement of priorities. P&A's priorities, which were discussed and decided on jointly by agency staff and members of the Advocacy Board, serve both as a useful template for agency planning, and as a basis for reporting on the current status of disability rights and services.

Listed below are brief descriptions of the issues chosen to receive priority attention from P&A. It should be noted that all the issues identified were considered important, but that, as indicated by the priority level assigned, not all can receive equal allocations of resources. *First Priority issues will be the subject of more extensive systemic initiatives than those identified as Second Priorities.*

**Rights of People in Institutions.** (First Priority Ranking) The discussion of this topic included recognition that people living in institutional environments were P&A constituents who were often among the most vulnerable to abuse/neglect and other deprivations of rights. These concerns are especially acute for people from cultural and linguistic minorities who may be isolated or whose needs may easily be misunderstood by caregivers not versed in their customs or culture. (e.g., people who primarily or exclusively rely on manual language or a language other than English). Evidence is mounting concerning quality of care issues in some institutions (e.g. nursing homes; some board & care homes, etc.) that impact on the ability to realize even basic rights (e.g. rights to adequate nutrition, freedom from restraint, freedom from exploitation).

While State-wide planning to implement the recent U.S. Supreme Court's decision in *L.C. v. Olmstead* is proceeding, it is raising serious questions concerning current capacity to provide community based choices and options for those seeking to live outside of institutional settings.

**Securing Rights under the ADA.** (First Priority Ranking) Discussion of this topic focused on both the universality of the ADA (e.g. its provisions potentially protect people with nearly all disabilities) – and the role P&A could play in promoting positive, proactive, win-win, efforts to secure compliance. The need to continue to focus on education, and to carefully choose issues for strategic enforcement was another point of consensus. As an example, the Office receives numerous complaints about inaccessible professional offices and businesses, unwillingness to provide for effective communication, etc. It appears that many of these entities could readily be made accessible, but that their proprietors are ignorant of either the law's requirements or readily achievable solutions to accessibility problems.

**Abuse and Neglect.** (First Priority Ranking) Abuse and Neglect are pervasive problems in all sectors of our society. P&A's emphasis will be developing approaches to enhance detection and monitoring in various facilities (e.g. group homes, foster homes, board and care homes); and on improving the agency's internal capacity to amass data and use it to promote prevention measures.

**Employment.** (Second Priority Ranking) Widespread unemployment and underemployment of working age people with disabilities has continued over the past decade, despite enactment of anti-discrimination laws, availability of innovative assistive technology, and desperation on the part of employers looking for qualified workers in a booming economy. To the extent that part of the problem is rooted in the traditional all-or-nothing system of subsidies and entitlements that many people with disabilities have come to depend on, things may be changing for the better. Passage of Work Incentives Acts by Congress and the Connecticut General Assembly, and other reforms being implemented by workforce development programs and the Social Security Administration promise to remove many current disincentives to employment. Discrimination remains a factor, but it was felt that P&A's limited resources should be focused not on mounting legal contests for employment discrimination, but rather on gearing up for advocacy issues likely to emerge as a result of these recent legislative initiatives. This was seen as a collaborative opportunity, with other disability programs (BRS, Independent Living Centers) and an opportunity to challenge prejudice and open a dialogue with the business community. Support for meaningful transition planning (e.g. school to work) was another need identified under this topic.



**Special Education.** (Second Priority Ranking) More people contact P&A about special education problems than about any other single issue area. Most of these callers are parents who are struggling with school systems that they perceive as consigning their son or daughter to inadequate, irrelevant and often affirmatively harmful educational programs. Based on the experience of agency clients and staff, these parents' perspectives are often quite valid. Railing against reimbursement formulas and accountability mechanisms, many school districts continue to see a "free appropriate public education" as an externally imposed program requirement rather than as a basic civil right of each child. A widespread shortage of special educators and a notable lack of competent inclusion specialists further compounds the problem. Indeed, even as there is a state-wide drive to prevent "over-identification" of special education students, many districts persist in placing children with disabilities into separate classrooms or schools, or even to suspend and expel them. These districts may be unconscious of the part they are playing in perpetuating rejection and segregation as the primary experiences of children with disabilities, but the parents of those children are not. Some school administrators have even resorted to coercion, requiring that parents agree to medicate their child as a condition for receiving special education services. For P&A, the question is: Given our limited resources, and the ineffectiveness of individual "due process" contests for effecting systems change, how can we make a difference?

**Community Inclusion** (Second Priority Ranking) The *Olmstead* case has forced advocates to assess the resources and structures necessary for community integration including safe affordable, accessible housing; accessible transportation systems; and, personal assistance mechanisms. All these are in short supply in most areas. Although hopeful approaches (e.g. self-determination project w/ DMR; Long-Term Care planning committee of the Olmstead coalition) have begun, the essence of community and the work required to effect genuine inclusion is not widely understood. In addition, capacity is lacking in all needed systems, and safeguarding mechanisms need to be established to prevent abuses. For example, as building codes have changed to encourage installation of sprinkler systems, requirements for "areas of refuge" (safe areas where people who cannot evacuate a building in the event of fire can wait for the arrival of fire fighters) have been reduced.

**People in the Criminal Justice System** (Second Priority Ranking) It is generally acknowledged that a significant number of people in jails and prison have mental health needs. Some have referred to the growth in the numbers of prisoners with mental illness as evidence of "re-institutionalization" of formerly hospitalized persons. Whether this analysis is accurate or not, it is clear that many of the people with psychiatric disabilities currently in jail for relatively minor offenses would not be there if other supports were in place in their lives. It is also clear from the increasing number of complaints P&A is receiving from people with disabilities who are incarcerated that there are problems with the overall treatment of adults and children with disabilities in the criminal justice system. Access to appropriate medical care, assistive devices, education-based rehabilitation, ADA required modifications, and alternative incarceration programs are a constant struggle.



**Assistive Technology** (Second Priority Ranking) Although technology - both sophisticated and simple - holds great liberating potential for people with disabilities, awareness about the availability of assistive technology, including rights to devices and services as part of certain funding streams, is limited. Existing loan programs are inadequate to meet the technology needs of individuals with disabilities who do not qualify for public funding programs.

**Leadership Renewal** (Second Priority Ranking) Over the past several years disability group leaders have noted that their ranks are thinning as they get older. There has been considerable discussion about the need to attract and support new leadership for the disability rights movement.

**Restraints** (Second Priority Ranking) Newly enacted federal and State laws require training and define specific limitations on the use of restraint and seclusion in most health care and residential environments. P&A will now receive notification of certain types of restraint related incidents, and will be better able to conduct investigations. However, despite the fact that increasing numbers of children with behavioral issues are being placed into self-contained classrooms run by local school districts, these safeguards do not apply in public school environments.

**Family Supports** (Second Priority Ranking) Families that include a person with a disability need more in-home, community based supports to challenge the maze of disability related issues. Often parents need help with creative solutions to address the problems associated with, but not limited to, waiting lists, transition from school to work, nursing and PCA shortages and the lack of support for children with mental health issues.

**Unmet Needs of Persons with Traumatic Brain Injury** (Second Priority Ranking) Despite lengthy litigation and a Title XIX waiver program, the needs of many people with acquired brain injuries go unmet. This is especially so for people whose problems include substance abuse and frequent brushes with the criminal justice system.

**Discrimination in Health Insurance** (Second Priority Ranking) Persons with disabilities repeatedly experience limited options, limited coverage and even total exclusion from private insurance plans. Medicaid offers a limited choice of medical providers while the process of obtaining durable medical equipment is often arduous, inefficient and frustrating. Medication costs further exhaust already limited budgets while managed care constraints deny access to necessary and in many cases, routine medical care. People who have progressively disabling conditions may need and benefit from skilled care but may not be eligible to receive reimbursement because their situations are unlikely to medically improve as a result of the care.

**Inspection of Facilities** (Second Priority Ranking) Licensing of facilities by Connecticut state agencies does not ensure positive living conditions for the residents of licensed living facilities in Connecticut. Community representatives and outside advocacy groups should routinely review such living conditions while monitoring the civil rights and community participation opportunities of the residents.

**Protection and Advocacy Outreach Efforts** (Second Priority Ranking) For an agency that is already beset with more demands for services than it can meet, the need to continually reach out to traditionally underserved groups can easily be forgotten. Nonetheless, failing to do so perpetuates inequities, and denies protection and advocacy services to vulnerable individuals with disabilities who may have great difficulty accessing and influencing service systems.

Additional copies of this publication may  
be obtained on our internet site or by request to:

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